



**DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health**

**Submission for OMB review; 30-day comment request; Genomics and Society
Public Surveys in Conjunction with Smithsonian Museum of Natural History
Genome Exhibit**

SUMMARY: Under the provisions of Section 3507(a)(1)(D) of the Paperwork Reduction Act of 1995, the National Institutes of Health (NIH) has submitted to the Office of Management and Budget (OMB) a request for review and approval of the information collection listed below. This proposed information collection was previously published in the Federal Register on April 25, 2013, pages 24427-24428 and allowed 60-days for public comment. No public comments were received. The purpose of this notice is to allow an additional 30 days for public comment. The National Human Genome Research Institute (NHGRI), National Institutes of Health, may not conduct or sponsor, and the respondent is not required to respond to, an information collection that has been extended, revised, or implemented on or after October 1, 1995, unless it displays a currently valid OMB control number.

DIRECT COMMENTS TO OMB: Written comments and/or suggestions regarding the items contained in this notice, especially regarding the estimated public burden and associated response time, should be directed to the: Office of Management and Budget, Office of Regulatory Affairs, OIRA_submission@omb.eop.gov or by fax to 202-395-6974, Attention: NIH Desk Officer.

COMMENT DUE DATE: Comments regarding this information collection are best assured of having their full effect if received within 30 days of the date of this publication.

FOR FURTHER INFORMATION CONTACT: To obtain a copy of the data collection plans and instruments or request more information on the proposed project, contact:

Laura M. Koehly, Ph.D., Senior Investigator, Social and Behavioral Research Branch, NHGRI, NIH, 31 Center Drive MSC 2073, Building 31, Room B1B54, Bethesda, MD 20892, or call non-toll-free number (301) 451-3999, or E-mail your request, including your address to: koehlyl@mail.nih.gov. Formal requests for additional plans and instruments must be requested in writing.

PROPOSED COLLECTION: Genomics and Society Public Surveys in Conjunction with National Museum of Natural History Genome Exhibit, 0925-NEW, National Human Genome Research Institute (NHGRI), National Institutes of Health (NIH).

Need and Use of Information Collection: The National Human Genome Research Institute's (NHGRI) strategic plan puts a strong focus on understanding more fully the societal implications of recent genomic advances. Currently, there is limited knowledge about the public's view regarding genomics and society. The newly opened exhibit at the Smithsonian National Museum of Natural History, "Genome: Unlocking Life's Code", provides a unique opportunity to obtain the perspectives of the public about the role of genomics in society. Surveys included in this project consider a broad range of topics related to Genomics and Society, including the following content areas:

- Beliefs about the role of genomics in health conditions and associated risk factors;
- The role of friends, family, media, and health professionals in gathering and communicating health risk information;
- Implications of genetics knowledge in understanding self-concept, race and ancestry;
- Opinions regarding genetics knowledge necessary for making legal, health, and lifestyle decisions.

The exhibit opened in June, 2013, and will reside at the National Museum of Natural History for fourteen months after which it will travel across the country. Data collection for this project is anticipated to begin fall, 2013 and continue through the course of the exhibit, including the time in which it will travel to other cities across the country. Data collection will occur under the direction of the National Institutes of Health (NIH) National Human Genome Research Institute (NHGRI) in partnership with the Smithsonian Institute's National Museum of Natural History.

Adults (18+ years) will be recruited through the exhibit using two different approaches. First, displays within the exhibit will offer visitors the opportunity to text responses to questions related to genomics and genomic information. Respondents will be sent an automatic invitation to complete online surveys and a link to the website containing these surveys. Text message content will be collected by a third party short code texting service that will remove personal identifying information from the text message responses. Second, participants will also be recruited via a link to the surveys on

the National Museum of Natural History's website. The URL for this survey site will also be advertised separately through media and social media channels.

The surveys will be available on a designated survey website hosted by the NHGRI. Visitors to the survey website can fill out the surveys if they choose. After completing an online consent confirming eligibility and a short demographic module, participants will be offered the option to complete one or more of the seven available surveys. In 2012, 7.6 million people visited the National Museum of Natural History. We estimate that our recruitment efforts will reach 3% of these visitors, 75% of whom will choose to complete one or more of the surveys. If these anticipated recruitment numbers are not met, a market research survey company may be used to recruit participants.

The data to be collected are primarily for research purposes; responses will be summarized and published in scientific journals as well as made available to the public through PubMed Central. Responses may also be used to inform community education programs sponsored by the NHGRI.

OMB approval is requested for 3 years. Three years will allow sufficient time to reach the anticipated sample size for this project, analyze the data, and disseminate the results. There are no costs to respondents other than their time. The total estimated annualized burden hours are 91,000.

Estimated Annualized Burden Hours

Survey Name	Number of Respondents	Number of Responses Per Respondent	Average Burden Hours Per Response	Total Annual Burden Hours Requested
Text Responses	228,000	5	1/60	19,000
Survey: Map Your Social Network	30,000	1	35/60	17,500
Survey: Health and Genetics from YOUR Point of View	30,000	1	25/60	12,500
Survey: Could Your Genes Predict Your Weight?	30,000	1	17/60	8,500
Survey: Kids, Genes, and Health	30,000	1	17/60	8,500
Survey: Celebrities, Prescription Drugs & Salmon	30,000	1	20/60	10,000
Survey: Will Genome Sequence Information Change How You View Yourself?	30,000	1	10/60	5,000
Survey: Exploring Our Identity: Genetics, Ancestry, and Race	30,000	1	20/60	10,000
Totals				91,000

Dated: July 15, 2013.

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National Institutes of Health.

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